



Friends of NIDCD

NEWSLETTER

February, 1990

FRIENDS OF THE NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS

NIDCD Appoints Dr. Snow Director



HHS Secretary, Louis W. Sullivan, M.D., has announced the appointment of James B. Snow, M.D., as NIDCD's first Director. Dr. Snow was Professor and Chairman, Department of Otorhinolaryngology and Human Communication, University of Pennsylvania Medical School.

The Director served as Medical Director for the University of Pennsylvania's Speech and Hearing Center, and its Taste and Smell Center. Additionally, he held appointments to Children's Hospital of Philadelphia, Graduate Hospital, Pennsylvania Hospital, Presbyterian-University of Pennsylvania Medical Center, and Veterans Administration Medical Center.

As a past member of the National Institute of Neurological and Communicative Disorders and Stroke's (NINCDS) Program Advisory Committee and its Advisory Council, Dr. Snow is well acquainted with the structure and policies of the National Institutes of Health. He brings his vast experience in medicine and research to the new Institute.

The Friends of NIDCD are delighted to welcome him and look forward to benefiting from his expertise and wisdom. We are confident that, under his guidance, the Institute will grow and flourish in a most productive way.

Congress Appropriates \$119 Million to NIDCD

On November 21, 1989, President George Bush signed the Labor-HHS Appropriations Bill (Public Law 101-166). Included in the Bill was Congress' recommendation of \$119 million for FY'90 for the National Institute on Deafness and Other Communication Disorders.

This figure represents an increase of 25.5% over the FY'89 allocation (the largest non-AIDS percentage increase of all the Institutes under the National Institutes of Health), and emphasizes Congress' strong commitment to the communicative disorders program.

We are tremendously indebted to the tireless efforts of Senator Tom Harkin of Iowa (Chairman of the Senate Appropriations Subcommittee), and Senator Arlen Specter of Pennsylvania (Minority Chairman of the Senate Appropriations Subcommittee) whose wisdom and guidance were instrumental in securing a strong financial base for the NIDCD.

Congressman William Natcher of Kentucky (Chairman of the House Appropriations Subcommittee) and Congressman Silvio Conte of Massachusetts (Minority Chairman of the House Appropriations Subcommittee) were equally supportive in their efforts to increase funding to this long-neglected area of scientific investigation. We want to particularly express our gratitude to them.

(Continued on back page)

Thanks to Dr. Moskowitz

As the NIDCD's new Director assumes his responsibilities, we want to express deep appreciation to Jay Moskowitz, Ph.D., Acting Director during its first critical year of operation. Dr. Moskowitz has worked tirelessly during this past year to insure a stable administrative foundation, a secure financial base, and a reliable support structure for NIDCD. We wish him well in his future endeavors and feel grateful to have had the advantage of his knowledge, devotion, and skillful direction.

Friends of NIDCD Established!

With the establishment of the *National Institute on Deafness and Other Communication Disorders* on October 28, 1988, the need to create an organization whose function would be to support expanded development of its research and training programs was evident.

Efforts to establish the *Friends of NIDCD* as a non-profit organization were initiated in February, 1989, and formally acknowledged by the Internal Revenue Service in December, 1989. Our Mission Statement is as follows:

Friends of NIDCD promotes public awareness about disorders of hearing, balance, speech, language, voice, taste, smell, and touch. The quality of life for 33 million Americans is significantly lowered because socialization and interaction with family, friends, and the entire community can be profoundly limited. Additionally, job opportunities are severely restricted.

Friends of NIDCD supports expanded development of research and training for the *National Institute on Deafness and Other Communications Disorders*, provides public education about issues before Congress, and promotes exchange of information among members. Contact groups include: physicians, parents, the elderly, schools for the hearing-impaired, educators, communication disorders professionals, organizations, volunteers, and communicatively impaired individuals.

The National Institute on Deafness and Other Communication Disorders

IN THE HOUSE OF REPRESENTATIVES:

APRIL 26, 1989

Testimony was presented before the *House Appropriations Subcommittee (Labor, Health and Human Services, and Education)*; The Honorable William H. Natcher (D-KY), Chairman, and The Honorable Silvio Conte (R-MA), Minority Chairman.

Testifying on behalf of the *Friends of NIDCD* for expanded development of research and training for the NIDCD were:

Geraldine Dietz Fox (*Executive Director, Friends of NIDCD*); Mr. Robert J. Cohn (*Program Analyst I, Pathology Lab, University of Michigan Medical Lab*); and Miss Rachel Dubin (*Student, Baltimore, MD*).

Others testifying for increased appropriations for the NIDCD were: The Honorable Claude D. Pepper (*The late United States Congressman: D-FL*); Jay Moskowitz, Ph.D. (*Acting Director, National Institute on Deafness and Other Communication Disorders*); Robert J. Ruben, M.D. (*Professor and Chairman, Albert Einstein Medical College, Yeshiva University; Chairman, Department of Otolaryngology, Montefiore Medical Center*); Mrs. Helen A. Mendelsohn (*Board Member, Neurofibromatosis, Inc.; Chairperson, NF-2 Sharing Network*); Mr. Howard E. Stone, Sr. (*Executive Director, Self-Help for Hard of Hearing People, Inc.*); Mr. Lawrence Meli (*Past President, Deafness Research Foundation*).

JULY 12, 1989

The House Appropriations Subcommittee recommended a funding level of \$99,952,000 for the new Institute during its "Mark-Up" session.

JULY 25, 1989

The Full House Appropriations Committee **APPROVED** the Subcommittee's funding recommendation.

OCTOBER 3-5, 1989

\$119 million for FY'90 funding for the NIDCD was **APPROVED** during the Senate and House Appropriations Committees' Conference.

OCTOBER 11, 1989

The \$119 million allocation was debated on the Floor of the House, and **PASSED**.

Persons Offering Testimony for NIDCD



Dr. Jerome C. Goldstein



Dr. Jay Moskowitz



Dr. Robert J. Ruben



Mr. Howard E. Stone, Sr.



Mrs. Helen A. Mendelsohn



Mr. Lawrence Meli

C O N C L U S I O N

OCTOBER 21, 1989

President George Bush **VETOED** the entire Labor-HHS Appropriations Bill, which included funding provisions for the NIDCD.

NOVEMBER 21, 1989

President George Bush gave final **APPROVAL** to the FY'90 Labor-HHS Appropriations Bill (Public Law 101-166).

IN THE SENATE:

MAY 12, 1989

Testimony was presented before the *Senate Appropriations Subcommittee (Labor, Health and Human Services, Education and Related Agencies)*; The Honorable Tom Harkin (D-IA), Chairman, and The Honorable Arlen Specter (R-PA), Minority Chairman.

Testifying on behalf of the *Friends of NIDCD* for expanded development of research and training for the NIDCD were:

Geraldine Dietz Fox (*Executive Director, Friends of NIDCD*); Ms. Cindy Campbell (*Vocational Rehabilitation Counselor for the Deaf, Division of Vocational Rehabilitation, Landover, MD*); Miss Rachel Dubin (*Student, Baltimore, MD*); Mr. Robert White (*World Renowned Tenor and Recording Artist*).

Others testifying for increased appropriations for the NIDCD were: Jay Moskowitz, Ph.D. (*Acting Director, National Institute on Deafness and Other Communication Disorders*); Jerome C. Goldstein, M.D. (*Executive Vice President, American Academy of Otolaryngology-Head and Neck Surgery*); Mr. Howard E. Stone, Sr. (*Executive Director, Self-Help for Hard of Hearing People, Inc.*); Mr. Lawrence Meli (*Past President, Deafness Research Foundation*).

SEPTEMBER 13, 1989

The Senate Appropriations Subcommittee recommended a funding level of \$121,116,000 for the new Institute during its "Mark-Up" session.

SEPTEMBER 13, 1989

The Full Senate Appropriations Committee **APPROVED** the Subcommittee's funding recommendation.

OCTOBER 3-5, 1989

\$119 million for FY'90 funding for the NIDCD was **APPROVED** during the Senate and House Appropriations Committees' Conference.

OCTOBER 19, 1989

The \$119 million allocation was debated on the Floor of the Senate, and **PASSED**.

IN MEMORIAM

On May 30, 1989, our Nation was saddened to lose one of its leading statesmen, Congressman Claude Denson Pepper. Mr. Pepper championed the rights of all people in three critical areas of society: civil and human rights, the needs of the elderly and underprivileged, and equitable health care.

His dedication to helping those afflicted with devastating health disorders is particularly visible at the National Institutes of Health in Bethesda, MD. As Sponsor or Co-Sponsor of 12 of the 13 Institutes, Mr. Pepper has been hailed as the "legislative father" of the NIH. On May 10, 1989, as a result of an Act of Congress, Building 31 (which houses the National Institute on Deafness and Other Communication Disorders) was appropriately christened the "Claude Denson Pepper Building."

We pay tribute to this remarkable man, without whom the NIDCD would not have been created; and we strive to carry on the legacy he has entrusted to our care.

Profile:

So many of you have had an opportunity to talk with Rosemary Davis on the phone that we thought you might like to know her better. Rosemary holds a Master of Science degree in Audiology from Gallaudet University and is a Member of both the American Academy of Audiology and the American Speech-Language-Hearing Association. Her professional appointments have included Assistant Professor of Audiology at Temple University Hospital Health Sciences Center in Philadelphia and Coordinator of Audiology at the Cincinnati Speech

and Hearing Center. She brings excellent management, organizational, and research skills to the "Friends," as well as an extensive background in developing educational and clinical uses for microcomputers.

In evaluating her role as Director of Research, Ms. Davis remarked, "The greatest rewards in life are received when people lend their strength and purpose to the achievement of an ideal whose roots are firmly anchored in promoting a better quality of life for all men."

Each of us, by virtue of being a part of society, has the responsibility of moving today's ideals closer to tomorrow's realities, and in so doing, positively impact the lives of those we touch. It is when these ideals and realities merge, that we realize that all of our individual efforts have together contributed to a visible manifestation of man's love for man.

From a professional and personal point of view, I feel privileged indeed to be associated with the Friends of NIDCD."





Miss Rachel Dubin greets a friend from last year's House Hearings, Congressman Steny Hoyer (D-MD).



The Honorable Edward R. Roybal (D-CA) meets with constituents to discuss appropriations issues for the NIDCD. Pictured (L-R) are: Dr. Paul H. Ward, Chief, UCLA School of Medicine; Congressman Roybal; Actress Nanette Fabray MacDougall; Dr. Howard House, Founder, The House Ear Institute.



The group gathers to share their experiences on the Hill (L-R): Dr. Walter Bejuke, Mr. Mori Rosenhalt, Mrs. Shirley Rosenhalt, Mr. Michael Cardozo, and Ms. Georgiana Fletcher.



Advocates meet congressional staff members in Senator J. Bennett Johnston's (D-LA) office. Front row: Ms. Alicia Azodeh (staff member), Mrs. Shirley Rosenhalt, Mrs. Adele Hauptman, Mr. Eduardo Gautier. Second row: Mr. Robert Luthmann, Ms. Alyson Azodeh (staff member), Mrs. Geraldine Dietz Fox, Ms. Audrey Sanabria, Dr. Walter Bejuke. Third row: Mr. Scott Trahan (staff member) and Mr. Carl Ross.



(L-R) Senator Mark D. Hatfield (R-OR) takes time to greet Mr. Robert White, Ms. Cindy Campbell, Miss Rachel Dubin, and Mrs. Geraldine Dietz Fox.



Congressman John E. Porter (R-IL) talks with Miss Rachel Dubin after the House Hearings.



Meeting in Senator Thad Cochran's office are: Miss Rachel Dubin, Senator Cochran (R-MS), and Ms. Cindy Campbell.

The NIDCD Appoints Advisory Board and Advisory Council

NIDCD is one of a few Institutes at the National Institutes of Health that has both an Advisory Board and an Advisory Council. Each of these entities has specific responsibilities.

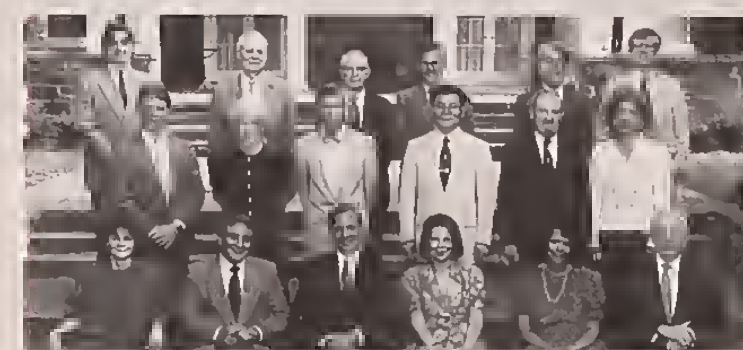
The Advisory Board is charged with setting long range plans and directives for the Institute. It reviews and evaluates the implementation of the national strategic research plan which was developed in January, 1989 by a Task Force (comprised of 200 specialists in the various fields) under the purview of the new Institute. The Board also advises and makes recommendations to the appropriate members of Congress and government administrators.

The Advisory Council is charged with evaluating research grants and programs, and providing recommendations for the implementation of those programs in conjunction with the goals and priorities set forth by the Board.

The Advisory Board and Council may each have 18 members: 12 members are scientists, physicians, educators, or other health professionals who have shown outstanding leadership in their fields; 6 members are from the general public and are knowledgeable about different aspects of the communication disorders field.

Both groups draw from the most qualified people in our country, and were selected from hundreds of applications received from the medical, scientific, professional, voluntary, and lay communities. Persons were chosen, not only for their expertise in a specific communication disorders field, but also to provide for balance in geographic distribution and minority representation.

The first meeting of the Advisory Board was held on June 26, 1989, and Geraldine Dietz Fox was elected its first Chairperson. The Advisory Council had its premier meeting on September 18, 1989.



Members of the NIDCD Advisory Board are (L-R): Seated: Dr. Lucille Beck (Representing Ex Officio Member, Dr. Gionvalli), Dr. Berlin, Dr. Moskowitz, Mrs. Fox, Dr. Sherry Mills (Representing Ex Officio Member, Dr. Dowdle), Dr. Gould, 2nd Row: Mr. Geoffrey Grant (Acting Executive Officer, NIDCD), Dr. Holland, Dr. Mozell, Dr. Lim, Dr. Michael, Dr. Holley, 3rd Row: Mr. Mell, Dr. Fellenhoff, Dr. Cooper, Dr. David Uddin (Representing Ex Officio Member, Mr. Newhall), Dr. Hart, Dr. Dobie. Not shown: Mr. Brown, Dr. Jordan, Dr. Menyuk.



Members of the NIDCD Advisory Council are (L-R): Seated: Mrs. Jaeger, Mrs. Glenn, Dr. Schwartz, Dr. Blumstein, Dr. Moskowitz, Dr. Miller, Dr. Moerland, Dr. Miyamoto, 2nd Row: Dr. Black, Mr. Grant, Col. Rodney Atack (Representing Ex Officio Member, Mr. Newhall), Dr. Countel, Dr. Ruben, Dr. Folkins, Mr. Stone, Dr. Sherrick, Dr. Bellugi. Not shown: Dr. Hanson, Ms. Matlin, Dr. White.

1990 Advisory Council

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The Salk Institute for Biological Studies

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Jay Moskowitz, Ph.D.
Acting Director
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and Legislation

Mr. David Newhall, III
Acting Assistant Secretary
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The Pentagon

William F. Rauth, Ph.D.
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National Institutes of Health

Friends of NIDCD

Board of Directors

Friends of NIDCD is proud to announce its 1990 Board of Directors:

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Executive Director
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Department of Otolaryngology
University of Texas Medical Branch

Ursula Bellugi, Ed.D.
Director, Laboratory for Language
and Cognitive Studies, and Professor,
The Salk Institute for Biological Studies

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Laboratory of the South
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Professor of Otolaryngology
Yale University School of Medicine

Paul H. Ward, M.D., F.A.C.S.
Professor of Surgery and Chief
Division of Head and Neck Surgery
UCLA School of Medicine



(L-R) Mr. Robert White, Ms. Cindy Campbell, Miss Rachel Dubin, Mrs. Geraldine Dietz Fox, and Senator Tom Harkin (D-IA) meet following the Senate Hearings.



Congressman Louis Stokes (D-OH) greets Miss Rachel Dubin after the House Hearings.



Testifying before the Senate Hearings are (L-R): Ms. Cindy Campbell, Miss Rachel Dubin, Mrs. Geraldine Dietz Fox, and Mr. Robert White.



Mr. Robert Corbin, Miss Rachel Dubin, Mrs. Geraldine Dietz Fox, and Congressman Steny Hoyer (D-MD) pause for a picture following the House Appropriations Hearings.



Ms. Sue Quantius (Staff Assistant) and Mr. Henry Neil (Staff Director) of Congressman William H. Natcher's (D-KY) staff pose for our camera.



Ms. Carol McGuire (Legislative Assistant to Senator Pete V. Domenici, R-NM) greets members of the group outside her office. Pictured are (L-R): Mr. Robert Luthmann, Mrs. Geraldine Dietz Fox, Ms. McGuire, and Dr. Walter Bejuke.



Congressman Bernard J. Dwyer (D-NJ) chats with Miss Rachel Dubin.



Mr. John Wagster, Legislative Assistant to Senator Jim Sasser, shares a moment with the advocates. (L-R) are: Mr. Robert Luthmann, Mrs. Geraldine Dietz Fox, Mr. Wagster, and Dr. Walter Bejuke.



Senator Ted Stevens (R-AK) meets with Ms. Cindy Campbell and Miss Rachel Dubin before the Senate Hearings.

Constituents Gather for a Day on Capitol Hill

On April 10, 1989, representatives from a variety of deafness and communication disorders groups gathered in Washington to meet with Senate and House Legislative Assistants of the Budget and Appropriations Committees.

Participants represented groups such as the Friends of NIDCD, Vestibular Disorders Association of America, American Tinnitus Association, Washington Metropolitan Area Tinnitus Self Help Group, Delaware Valley Tinnitus Association, Staten Island Tinnitus Association, Better Hearing Institute, Hearing Industries Association, American Speech-Language-Hearing Association, and the Deafness Research Foundation.

The congressional staffs were warm, enthusiastic, and receptive to the group's message—the need for expanded development of research and training for the NIDCD. Of particular interest to the staff was the opportunity to speak directly with individuals afflicted with these disorders.

We were delighted to meet Alyson Azodeh, who is profoundly hearing-impaired, of Senator J. Bennett Johnston's office. Senator Johnston (D-LA) has been instrumental in organizing staff signing lessons, and in bringing awareness and sensitivity to his Washington office about issues affecting deaf persons in America.

As an exhausted, but satisfied, group disbanded to return to their respective daily routines, one person commented, "It is a wonderful tribute to our democratic system that an individual can walk into any congressional office in Washington, and be heard. It is evident that if we all band together as a unit, we can effect significant changes in the communicative disorders field for ourselves and for our children."



Miss Rachel Dubin tries out Congressman Joseph D. Early's congressional seat following the House Hearings. Pictured are: Miss Dubin, Mrs. Geraldine Dietz Fox, and Congressman Early (D-MA).



Constituents gather after a day on Capitol Hill (L-R): Mr. Eduardo Gautier, Ms. Dinah McElfresh, Mr. Moigan Downey, Ms. Michele Hartlove, Mr. Robert Luthmann, and Mr. Carl Ross.

From the Executive Director: Geraldine Dietz Fox

Friends of NIDCD experienced immense growth during 1989! By the time we testified before Congress, 244 organizations, schools, and agencies (representing 2½ million people) joined our group in support of expanded development of research and training for the National Institute on Deafness and Other Communication Disorders.

Throughout the year, thousands of persons (physicians, professionals, parents of children with communicative disorders, teachers, volunteers, senior citizens, and individuals) wrote letters, visited, or sent telegrams to their congressional leaders.

The success of this united effort was noted when the NIDCD was awarded an unprecedented \$119 million for FY'90.

I want to take this opportunity to thank each and every one of you. Your willingness to join with others to promote finding the causes, preventions, and cures of deafness and other communication disorders has made all the difference!

We have a long road ahead and much left to accomplish; but we accept these challenges, knowing that great achievements are possible when people band together to reach a common goal.

In the words of our late, beloved Congressman Claude Pepper: "So long as life lasts, men hope to go forward and upward in their course, to dream dreams, and eventually to soar beyond the summit of the highest clouds."

May each of you find peace, health, and happiness in the coming New Year.



Mrs. Geraldine Dietz Fox, and Miss Rachel Dubin meet with the Chairman of the House Appropriations Subcommittee, Congressman William H. Natcher (D-KY).

Congress Appropriates... (continued from first page)

Indeed, all the Members of both the Senate and House Appropriations Subcommittees showed enormous enthusiasm and optimism for what the NIDCD will accomplish. We are listing Subcommittee Members' names and states and encourage everyone to write a short note of appreciation for the exceptional work our Congressmen have done this past year and to ask for their continued support for issues affecting NIDCD for FY'91.

Letters can be sent to:

In the Senate:

The Honorable _____
United States Senate
Washington, DC 20510

In the House:

The Honorable _____
United States House of
Representatives
Washington, DC 20515

Salutation:

Dear Senator _____ :

Dear Congressman/woman _____ :

HOUSE OF REPRESENTATIVES 1990 APPROPRIATIONS SUBCOMMITTEE

Labor, Health and Human Services, Education

Democrat

William Natcher, KY, Chairman

Neal Smith, IA	Joseph Early, MA
David Obey, WI	Bernard Dwyer, NJ
Edward R. Roybal, CA	Steny Hoyer, MD
Louis Stokes, OH	

Republican

Silvio Conte, MA, Minority Chairman

Carl D. Pursell, MI	C.W. Bill Young, FL
John E. Porter, IL	Vin Weber, MN

SENATE

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and Related Agencies

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Ted Stevens, AK	Thad Cochran, MS
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Celia Dietz	Cola Jackson